



- Flu vaccine clinic open to NIH staff Oct. 3 - Nov. 10
- Dr. Majid Tanas named chief of Pharmacy Department

New art exhibit shows how medicine rocks at NIH

The NIH Clinical Center, in partnership with the Smithsonian Institution, held a ribbon cutting ceremony Sept. 12 for a new Minerals in Medicine exhibition showcasing more than 40 minerals crucial to human health and biomedicine. The minerals will be on display for 18 months.

The exhibit's crystals and minerals, on loan from the National Museum of Natural History, are not only interesting to admire but also allow spectators to learn about their important roles in keeping the human body healthy. The minerals enable the creation of life-saving medicines and cutting-edge medical equipment used in the NIH CC and healthcare facilities worldwide.

"This exhibit is a product of a great partnership between Dr. Jeffrey Post and his colleagues at the Smithsonian's Museum of Natural History and the NIH Clinical Center," said Dr. John I. Gallin, director of the NIH Clinical Center. "It is really a treat to be able to display the natural beauty of these magnificent crystals that contain elements vital to human health. We hope our staff, visitors and patients smile when looking at these miracles of nature."

Prominently placed near Admissions on the first floor, the exhibit is seen by hundreds of people on a daily basis. Dr. Bob Range, a hospital dentist with the National Institute of Dental and Craniofacial Research who works in the CC, recently visited the exhibit and found



Dr. John I. Gallin, director of the Clinical Center, and Dr. Jeffrey E. Post, chair of the Department of Mineral Sciences and Curator of the National Gem and Mineral Collection at the Smithsonian Institution National Museum of Natural History, launch the exhibit.

restorations and pour impressions in stone to fabricate removable and fixed prostheses," said Range. "It is quite remarkable to see some of these materials on display in their unprocessed organic form. The stones are stunning."

Similarly, Dennis Johnson, a computerized tomography (CT) technologist in the CC Radiology and Imaging Sciences Department, enjoyed viewing the Huebnerite with Quartz from Pasto Bueno, Peru, which is used in CT imaging.

"The minerals are absolutely gorgeous and intriguing," said Johnson. "The Huebnerite with Quartz is very fascinating to see. This is source of tungsten in its rawest form. Tungsten is used in the target of the anode portion of an X-ray tube (located in a CT scanner). It is imbedded in a copper block, which is the part of the X-ray tube bombarded by the electron beams to produce x-rays."

View photos of the minerals, including local minerals from Maryland and Virginia, at CC News online: <https://go.usa.gov/xKeQQ>

particular interest in the minerals used in dentistry, including Gypsum, Calcite with Marcasite and Fluorapatite with Calcite.

"Naturally occurring stones and minerals have long been an essential staple of dental materials – allowing providers to clean and strengthen teeth, create anatomical

Dept. of Bioethics celebrates 20 years of asking hard questions, strengthening scientific research, protecting clinical trial participants

This fall, the NIH Department of Bioethics, located in the Clinical Center, will celebrate its 20th anniversary. The small staff of multidisciplinary bioethicists, some supported by the CC and some by other institutes and centers, conduct and publish their own research and run a Bioethics Consultation Service, which clinicians, investigators, patients and their families can use to discuss ethical issues in research and in caring for patient subjects during the course of research. The department also has a well-regarded bioethics fellowship training program,

which has trained more than 100 bioethics fellows, and hosts Ethics Grand Rounds for the NIH community, which draw roughly 500 attendees every year.

From thinking about how scientists do rigorous research during a humanitarian crisis; to properly consenting patients who have cognition-impaired diseases; to the logistics of future research using crowd sourcing and online portals; the department explores approaches to tough scenarios, often where there's not a precedent.

BIETHICS page 3

Town Hall encourages staff participation in focus groups

On Sept. 7, the NIH hosted a Town Hall meeting to discuss new opportunities for Clinical Center and NIH staff to voice suggestions on patient care and the overall practice and process by which the NIH carries out its research mission in the CC.

It was announced at the meeting, held in Masur Auditorium, that a series of focus groups will be organized in the coming weeks to allow for input. All staff are encouraged to learn more about how to become an active partner in the important decision-making process by signing up for a focus group on the intranet, at <http://intranet.cc.nih.gov/focusgroups.html>. As of Sept. 26, more than 340 people have signed up to participate and 13 focus groups have met.

Attendees heard from Stewart Simonson, the former Assistant Secretary for Public Health Emergency Preparedness at the U.S. Department of Health and Human Services, who will facilitate the focus group sessions. Simonson has a long history of working closely with the NIH on matters of public health interest, including the development of the Special Clinical Studies Unit, and is a skilled facilitator.

Simonson will work closely with a Steering Committee consisting of senior NIH clinical leadership and a Clinical Care Group consisting of clinical care providers and CC staff from all levels of the organization. The groups will help formulate specific recommendations for changes based on the feedback obtained.

NIH staff, view the videocast: <http://go.usa.gov/xKtC6>

Flu vaccine clinic open to NIH staff Oct. 3 - Nov. 10

The NIH Office of Research Services and the Clinical Center will provide free flu shots to staff with a valid NIH identification badge from Oct. 3 through Nov. 10. View the complete schedule: <http://go.usa.gov/xDP6w>. To learn more about availability and locations, call 301-496-2209.

The best way to reduce the risk of getting the flu is to get the flu shot every year. By getting the flu shot, healthcare personnel can also reduce the risk of exposing patients to the influenza virus. All staff who have patient contact, including both employees and contractors, are required to get the flu vaccine each year. For all other NIH staff, immunizations are available but not required.

Opening at 8:00 or 8:30 a.m. most days, the clinic is located on the east side of the 7th floor of the Clinical Research Center. On select days, the clinic will open at 6:00 a.m. and close at 7:00 or 8:00 p.m. to accommodate a variety of schedules. Employees, please wear clothing that does not restrict access to the upper arm. Changing areas will not be available.

Starting Oct. 13, there will also be off-campus sites providing free flu shots. Shady Grove, Bayview, Poolesville, Neuroscience Center, Fishers Lane and Rockledge locations are included on the schedule.

The NIH ordered both high-dose (<http://go.usa.gov/xDPHm>) and the regular quadrivalent vaccines for all flu shot sites. Staff who are age 65 and older can receive the high-dose vaccine. A limited number of egg-free doses have been ordered and will only be administered to health care personnel with a documented egg allergy.

Sidelined by severe aplastic anemia, local student finds hope in clinical trial at NIH

Hadley A. Graham traded in her school books for a clinical trial at the NIH Clinical Center. In April of this year, Graham was a junior at George Mason University, focused on maintaining her 4.0 GPA by studying and doing well on her upcoming finals. The healthy, active 21-year old had a full academic schedule and extracurriculars like cheerleading and running. She was studying kinesiology with plans to eventually earn a doctorate in physical therapy.

Then, in mid-April, she ran a 10K race and found that it was a struggle to finish. Graham, who had run these types of races before with ease, thought that something was wrong. She also began noticing bruising and fatigue, and her joints started to hurt. But, she was in the last week of finals and dismissed these symptoms by blaming them on the stress of finals, studying and pulling all-nighters in preparation for exams.

By May, "I couldn't make it up the stairs and was not able to breathe," Graham said.

Her parents took her to the family doctor bright and early on a Monday in mid-May, unaware that their lives would soon change dramatically.

"We were back in on Tuesday morning for the screening of the lab results. Hadley had an appointment with an oncologist by 1 p.m. that afternoon, and they did a bone marrow biopsy the same day. We got the diagnosis of severe aplastic anemia by 3 p.m.," said her mother Diane Graham.

Severe aplastic anemia is a rare disease; only 600 to 900 people are diagnosed each year. With this disease, the bone marrow stops producing enough of the three types of blood cells: red blood cells, white blood cells and platelets. Untreated, it can be fatal.

Hadley's first reaction to the diagnosis was shock and anger. "I couldn't believe it," Graham said. "I thought, 'that can't be right'; I have classes today. I was praying to God. I was very scared."

Within 48 hours of the diagnosis, Graham was hospitalized due to complications from severe aplastic anemia.

"While there, she received a platelet transfusion, and that is when the oncologist told us about the clinical trials at NIH," Diane said.

Bone marrow transplant is one possible treatment for severe aplastic anemia. However, it's not an option for Graham who was adopted from Korea. Graham was lucky, though; she fit the parameters for an ongoing clinical trial for severe aplastic anemia at the NIH Clinical Center. The clinical trial she is participating in tests the safety and effectiveness of adding eltrombopag, which is

used to increase the number of platelets, to standard immunosuppressive therapy for severe aplastic anemia.

On May 31, just two weeks after learning her diagnosis, she was admitted to the NIH Clinical Center for the clinical trial. To attend the treatments, Graham had to drop out of the summer semester.

"I was really mad I couldn't go back to school. I had a plan, and being sick was not part of the plan," Graham said. "But, there is one good thing to come out of this – we are lucky to have NIH!" Her mother agreed.

"We have not had one bad experience here. Every nurse, doctor and staff member we have seen has been so kind and so interested in Hadley. They don't have to go out of their way to see us, but they just do it," Diane said. "As a parent, it is so hard to see your child go through this. I never worried about my kid getting a rare disease. It is so reassuring that NIH is here; that smart people like Dr. Neal Young and Dr. Danielle Townsend are here to take care of Hadley."

Young, a Senior Investigator in the Cell Biology Section of the National Heart, Lung, and Blood Institute, said, "Without patients like Hadley, we wouldn't be able to do the clinical research that should benefit not only her, but everyone with these types of diseases. We think that Hadley is going to get the best possible care for severe aplastic anemia here at the Clinical Center even though that care is through a research trial."

Throughout the trial and her experience, Graham said she has learned some important truths.

"To me, I'm still just a normal kid trying to live a normal life. This disease doesn't define who I am. Don't let a disease define who you are," she said. Being sick has also reminded her of the importance of having family and friends by your side. And, finally, "if you have a health issue, go to the doctor to get it checked because your health is so important," she said.



Hadley Graham points to her IV infusion of blood while under going treatment at the CC.

Read more online! Scan the barcode or visit www.cc.nih.gov/about/news/newsletter.html



- Battery running low? Mobile device charging stations now available for patients, guests
- National Symphony Orchestra performs

Use a downloaded app on a smartphone or tablet to scan the Quick Response (QR) barcode. You will be directed to the CC News online.

Clinical Center News

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Published monthly by the Office of Communications and Media Relations, Justin Cohen, chief

News, article ideas, calendar events and photos are welcome. Submissions may be edited.

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BIOETHICS *from page 1*

Bioethics is “a discipline which involves inquiry into the right way to behave and the right kind of person to be in the life sciences, biomedical research, healthcare, medicine and public health,” according to Dr. Christine Grady, chief of the Department of Bioethics. Grady, along with a couple of others on her team, have been with the department since it began in late 1996.

According to Grady, Dr. John Gallin, the director of the CC, “had the idea that bioethics was important and needed more visibility so in 1995 he convened a group of people from around the country to advise him on what a department of bioethics could do at the NIH. Based on that, he created the department.” In 1996, Grady served as acting chief of the department until Dr. Ezekiel J. Emanuel came in 1997 to serve as the founding chair of the department. For over two decades, Emanuel ran the department. With his departure in 2011, Grady again served as acting chief until she was named chief in 2012.

While the department isn’t nearly as old as the CC, which celebrated its 63rd anniversary this year, attention to bioethics has been woven into patient care and clinical trials prior to the department’s formal creation at NIH – and prior to the creation of any regulations about informed consent and institutional review boards.

“Bioethics is a relatively young field,” Grady said. “The idea of it really emerged in the 1970s. So, the Clinical Center had already been open for about 20 years at that point. However the Clinical Center has a history that’s unique in terms of thinking about the ethics of research. From the day that the doors opened, there was a plan for group review of protocols to assess the ethics and protect the rights of individuals who were in them.”

The expertise the Department of Bioethics provides goes beyond the CC.

Many of the NIH institutes and centers request consultations, and department staff are asked to join NIH committees on different projects. Even different agencies across the government turn to the department for guidance.

“We try very hard to foster an environment where people think about ethics in a positive way. There is often a lot of hesitation on the part of clinicians and researchers to get advice from anyone who has an ethics label. There’s this worry that asking a question has the implication that you’ve done something wrong,” said Dr. Marion Danis, head of the Bioethics Consultation Service within the department. “We, in consulting, provide an open space for thinking together. We really want to create a place for moral dialogue.”

Grady added, “Sometimes people hear the words, ‘ethicist’ or ‘bioethicist,’ and they think those are the people who tell you what you can’t do. From the beginning, we have tried to do exactly the opposite. Rather than telling people what they can or can’t do, we try to help them think through what’s ethically going on in a particular situation and help them to identify possible options for proceeding, as well as the reasons that one option might be ethically preferable to another.”

As new issues arise over the next five to 10 years, and science leads researchers in different directions, the department will be able to pivot and take on the ethical issues that advancing technologies present.

“We’ll be positioned to take what we know and what we do and apply it to new situations,” Grady said. She foresees neuroscience to be one possible area of research that will only continue to grow in importance and complexity. In the years to come, Grady believes that bioethics will focus on health policy and priorities that effectively and equitably promote healthcare delivery to populations across the country.

Off-campus housing to open for Jewish patients, caregivers

In 2017, an off-campus home run by the non-profit organization Bikur Cholim of Greater Washington will open at full capacity for Jewish patients being treated at the NIH Clinical Center, along with their family members and caregivers.

The Bernard Creeger Bikur Cholim House, which is located just steps from the Center Drive NIH entrance on Old Georgetown Road, will help patients and family members who either cannot stay in The Children’s Inn at NIH or the Edmond J. Safra Family Lodge due to extended stays or whose religious needs cannot be completely met in other types of lodging.

The home, which is undergoing renovation, is currently open for limited use for a few patients in great need of a place to stay. The house will eventually accommodate three to four families at a time. A ribbon-cutting ceremony will take place at the official opening in spring 2017, once renovations are complete.

“This is a home of hope and healing for Jewish patients and their families,” said Audrey Siegel, executive director of Bikur Cholim of Greater Washington. “Guests will have access to a kosher kitchen and kosher food and there will be special amenities for the Jewish Sabbath and holidays. It will also serve as an additional place of refuge and respite for those staying on the campus but who want a Sabbath meal or holiday celebration.”

Siegel said that one family from this summer told her, “We look around us and we say a million times a day how lucky we are that we are able to stay at this house. It’s the only way that we could have the treatment here.”

In the Jewish faith, Bikur Cholim refers to a commandment to visit and care for the sick. Bikur Cholim of Greater Washington builds upon this facet of Judaism to care for Jewish patients and their families in the area at no cost, including those at the NIH Clinical Center. They have provided sponsor families for patients to stay with and other services for nearly two decades.

“Community-based organizations such as Bikur Cholim are a vital part of the social support network NIH patients and families need in order to obtain and continue medical treatment throughout a trial at the NIH Clinical Center,” said Social Work Department Chief Kathy Baxley.

The CC Social Work Department supports patients and their families with their lodging needs and can help with situations where financial assistance is needed. Patients or care providers, for more details, please call the Clinical Center Social Work Department at 301-496-2381, or the non-profit at 202-331-4481.

Pediatric patient receives surprise birthday party



On July 28, nurses, doctors and care providers came together in the NIH Clinical Center pediatric clinic for a surprise birthday party for Hakim Frazier Harris (center). Frazier Harris, who turned 23, has been coming to the Clinical Center since October 2015 on a National Cancer Institute protocol for synovial sarcoma. Growing up in the foster care system, he didn’t always have birthday celebrations, which drove his NIH family to make this year extra special. Read more at CC News online: <https://go.usa.gov/xKeQQ>

Dr. Majid Tanas named chief of Pharmacy Dept.

The NIH Clinical Center welcomed Dr. Majid Tanas in August to serve as the new chief of the Pharmacy Department. The Pharmacy Department provides medicines for inpatients and outpa-



Dr. Majid Tanas, chief of the NIH Clinical Center Pharmacy Department.

tients on NIH intramural research protocols at the NIH Clinical Center. Under Tanas' leadership, pharmacists will continue to manage commercially available and investigational medications in approximately 1,000 research protocols, including 200 blind studies.

"I look forward to working to develop a world class operation and patient service in a modern health-care system!" Tanas said.

He is a nationally recognized leader in the area of research pharmacy management and services. Prior to arrival at the Clinical Center, he worked at the Oregon Health and Science University as assistant director for Oncology, Research Outpatient, Ambulatory, Specialty, and Transitions of Care Pharmacy Services. At the university, Tanas successfully integrated best practices into the large scale academic hospital pharmacy system.

In addition, Tanas has managed a network of outpatient pharmacy services and specialty and transition of care pharmacy services that became Utilization Review Accreditation Commission specialty pharmacy certified. He has also leveraged process improvement methods and techniques in research pharmacy services, resulting in significant increases in patient safety, operational efficiency and financial savings.

Tanas' expertise and leadership will benefit the Clinical Center greatly during this challenging time of increasing regulatory oversight and skyrocketing pharmaceutical costs.

Since July 2015, Dr. Barry Goldspiel has served as acting chief of the department.

American Nurses Association formally recognizes the profession of Clinical Research Nursing

In hospitals across the country, registered nurses are often certified for their advanced knowledge in medical specialties such as oncology, critical care, behavioral health or pediatrics. But for the nearly 1,000 clinical research nurses (CRN) and research nurse coordinators working in the

NIH Clinical Center, the opportunity never existed to receive a certification or recognition of their unique skillset as an integral part of the research team throughout the clinical research trial process. In August, after years of hard work by the NIH Clinical Center Nursing Department, in collaboration with the International Association of Clinical Research Nurses (IACRN), the American Nurses Association announced that it is now officially recognizing the profession of clinical research nursing as a specialty practice.

"There's nowhere in the world, beyond the Clinical Center, that has a thousand CRNs in one location. The Nursing Department and our nursing colleagues throughout the NIH have truly pioneered the way for defining and creating a better understanding of the newly recognized specialty of clinical research nursing," said Dr. Gwenyth R. Wallen, acting chief nurse officer in the NIH Clinical Center Nursing Department. "What we and all CRNs do is critically important in advancing science and medicine across the globe."

CRNs serve as a critical member of the medical team involved in the clinical



Staff from 3NE in the Clinical Center, including many Clinical Research Nurses (CRN), gather together in celebration of the American Nurses Association's recent recognition of CRN as a specialty practice.

research process, quality of the research outcomes and the safe, expert care of research participants. The roughly 600 Clinical Center and 400 institute staff working as CRNs in the Clinical Center, including research nurse coordinators, focus on the care of their patients blended with a knowledge of the

scientific process, research regulations, ethical principles and data collection, analysis and interpretation.

"We hope our patients, doctors and others in the healthcare community will feel very proud and confident with the expertise and specialty knowledge that our nurses possess," said Dr. Cheryl A. Fisher, senior nurse consultant in the Nursing Department.

For nearly 10 years, the Nursing Department has taken steps to develop the conceptual model for the CRN and increase the understanding and recognition of it as a profession. Staff have been actively involved in IACRN committees on research, education, marketing, and, most importantly, scopes and standards.

In addition, the Nursing Department published their own research studies on clinical research nursing across the country, validated within the NIH Clinical Center. The publications in *Nursing Outlook*, *Oncology Nursing Forum* and the *Journal of Clinical and Translational Science*, helped the ANA shape their understanding of the scopes and standards which define the role of a CRN and the parameters that need to be met to certify future CRNs.

Upcoming Events *View lectures online: <http://videocast.nih.gov>*

Combined Federal Campaign (CFC) Charity Bake Sale: Bake a Difference

Oct. 19, 2016, 11:00 a.m. – 1:30 p.m.
Outside of the 2nd floor cafeteria
Sales to benefit the CFC. Baked goods competition will be judged at 11:00 a.m. Winners announced at Noon. Contact Heather Bryant for more details: 301-451-5168, heather.bryant@nih.gov.

John Doppman Memorial Lecture for Imaging Sciences: Radiogenomics: Leveraging Multi-Scale Data to Drive Biological Insights in Oncologic Biomarker Development

Oct. 26, 2016, 12 noon – 1:00 p.m.
Lipsett Amphitheater
Presented by Dr. Michael D. Kuo, University of California, Los Angeles.